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The epilepsy nurse specialist—expendable handmaiden or essential colleague?

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The benefits of a specialist epilepsy nurse in the management of people with epilepsy are still in question. Evidence from controlled clinical trials suggests that patients supported by a nurse specialist are well informed and have a high degree of satisfaction. However, no significant effect on health status or the number of seizures has been yet demonstrated, although this is not the primary function of most epilepsy specialist nurses.

The recent International League Against Epilepsy (ILAE) British Branch meeting in Liverpool (April 2001) dedicated a one-day symposium to epilepsy nursing including a debate on the effectiveness of 'the epilepsy specialist nurse—warm fuzzy feeling or evidence based?'. Although it was agreed that evidence-based research is limited, the case studies and data presented, throughout the symposium, highlighted the varying role of the epilepsy specialist nurse in supporting both the specialist physician in epilepsy care, the non-specialist physician and the primary care physician in patient communication. This paper provides an overview of the presentations given at the symposium, including those on nursing research and publishing.

Key words: epilepsy; nursing; specialist; research; publishing.

INTRODUCTION

Epilepsy nurses often need to justify their role in the management and treatment of patients with epilepsy. This is most apparent in the area of funding, where many bodies do not recognise the benefit of an epilepsy specialist nurse (ESN) and feel limited resources would be better spent elsewhere, or on a generic nurse rather than a specialist nurse.

At the International League Against Epilepsy (ILAE) British branch meeting held in Liverpool in April 2001, a one day symposium debated the effectiveness of the epilepsy specialist nurse: 'warm fuzzy feeling or evidence based?'. Although it was agreed that current evidence-based research is limited in scope, and has probably been asking the wrong questions, the case studies and data presented highlighted the varying roles of epilepsy specialist nurses, in the clinic and in primary care and in patient communication. The presentations of the varying roles that epilepsy nurses now have illustrated just how much epilepsy nurses have advanced in a short time, raised the obvious question as to how far their role could be extended, particularly into that of clinical responsibility rather than just a support role. The symposium raised more questions than it answered, but caused the audience to reflect on the developing responsibility of the epilepsy specialist nurse—a theme that the next ILAE British Branch meeting, to be held in Exeter in April 2002, will return to.

EPILEPSY NURSING IN THE UK: PAST AND PRESENT

Nurse specialists

Specialist nursing was first developed in the 1970's as an alternative to the Salmon career structure[1]. The first nurse specialist was in neurosurgery, at the Manchester Royal Infirmary. The idea was quickly adopted by the Royal Marsden Hospital, London, which specialised in cancer and recognised the need for nurse specialists to keep up to date with the constant changes in cancer treatment and technology.

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At this time, the nurse specialist was called a 'clinical nurse specialist'. Subsequently, the titles have changed many times and the definition of the nurse specialist has become confusing; there have been up to 100 different titles for nurse specialists and their qualifications vary (as does their recognition) across different clinical areas.

This ambiguity is unacceptable and is not in accord with the public protection role of the United Kingdom Central Council for Nursing, Midwifery and Health Visiting. To protect the public from nurses whose training is ambiguous and perhaps incomplete, the government is introducing a new structure for the nurse specialist. The structure has four levels based on competency, knowledge and skills, and will have pay bands for each level.

Epilepsy nurse specialist

Epilepsy care in the UK tends to be fragmented; there is often insufficient co-ordination between primary and secondary care providers and a consequent lack of information for the patient[2]. Working across professional and organisational boundaries, the perceived objective of the nurse specialist is to consolidate epilepsy care by liasing with multidisciplinary health professionals and co-ordinating patient care, in addition to informing and supporting patients: it is not, currently, related to directly providing therapy, although some nurses are starting to have a diagnostic and therapeutic role. 1973 saw the first epilepsy specialist nurse appointed in Doncaster. In the late 1980's and 1990's epilepsy care advanced significantly with the development of new drugs and technology. As the area changed rapidly, nurse specialists, many of whom were working in isolation, came together to form the epilepsy specialist nurse association (ESNA). Currently, there are 282 members of ESNA, although not all epilepsy nurses in the UK belong to this organisation.

Present state of epilepsy nursing in the UK

At present, there is no consensus on the required qualifications for the epilepsy specialist nurse. The majority have community nursing experience, an English Nursing Board qualification or a professional diploma; a minority have a B.Sc. or Masters degree, but there are no Ph.Ds registered.

The role of the epilepsy nurse specialist is varied, but centres around informing and supporting the patient. This role may change, as the NHS Plan 2001 estimates that by 2004 over half of all nurses will be able to prescribe medication. The change in prescribing powers will be set out in a potential new Health and Social Care Bill, which plans to amend the Medicines Act 1968. A change to prescribing has implications for the epilepsy specialist nurse, who may be granted the power to prescribe medicines that cover certain conditions, including epilepsy.

The issues of qualification and prescribing need to be considered in the context of epilepsy nursing. If the role of the nurse specialist in improving patient care is to be developed, there is a need to have nationally agreed qualifications and discussion on the implications of nurse prescribing. These issues will be debated at the next ILAE British Branch meeting in Exeter in April 2002, as will the role of the nurse consultant.

The meeting next examined the various roles that individual epilepsy nurses have developed, either for themselves, or with the encouragement of the their consultant or employers.

VARYING ROLES

Nurse triage clinics

These nurse-led clinics rapidly identify and investigate patients who have experienced their first seizure and have been referred from accident and emergency (A & E) or their own general practitioner (GP). The nurse specialist running such a clinic can also identify patients who do not have epilepsy and, therefore, avoid referring these cases to a consultant.

At these fast-track triage clinics, the nurse specialist takes a detailed history, arranges appropriate tests (including an electro-encephalogram) and gives advice to the patient. A patient leaving this clinic will have a follow-up appointment arranged and be given a point of contact at the clinic, for further treatment.

An audit of the fast-track nurse triage clinic at Leicester showed that of 33 patients who attended the clinic, 21 had been diagnosed with epilepsy (13 of whom started medication) and 5 had experienced a one-off seizure. Patients were satisfied with the clinic, the speed of the service and the advice given. For the doctors, these nurse-led fast-track clinics mean that patients who are referred to them come prepared, having undergone the appropriate tests. A & E are also happy with the service provided by the clinic, as they now have somewhere to quickly refer patients with suspected epilepsy.

Secondary care liaison nursing

Such a service needs to establish links with GP's, practice nurses and midwives in an effort to improve

epilepsy care and identify patients who are in need of a treatment review.

General Practitioners can be invited to an educational session on epilepsy, which can have the incentive of post graduate education allowance points. Such a session aims to increase the knowledge and awareness of epilepsy and allows the nurse to establish links with the GPs in his or her area thus increasing direct referrals.

Practice nurses can also be targeted, encouraging them to audit their patients and to identify those patients with epilepsy who may need their treatment reviewed. Practice nurses can be supplied with a letter inviting patients to a specialist review and a questionnaire and a review form. In the epilepsy nursing service at Northamption hospital, half the patients contacted by their practice nurse responded to the letter and half of those were subsequently reviewed by the hospital clinic.

By establishing links with GP's and practice nurses, patient care is improved, as is the confidence of GP's in dealing with epilepsy. The nurse specialist also acts as point of contact for advice on issues relating to epilepsy. 'Link Midwives' can be trained to increase awareness of epilepsy among obstetricians.

Patients with learning disabilities

Epilepsy patients with a concomitant learning disability require the specialist care of a learning disability epilepsy specialist nurse. To ensure epilepsy patients are receiving comprehensive care the learning disability epilepsy specialist nurse establishes joint clinics with consultant psychiatrists and paediatricians and develops links with the emergency services. An epilepsy nursing assessment form may help to identify the patient's needs.

A key role for the epilepsy specialist nurse working in leaning disabilities is involvement in the treatment and management of patients with epilepsy. There is a great demand for training carers, including how to manage seizures. Acting as a link between primary and secondary care, the learning disability nurse can facilitate fast-track treatment.

Children with epilepsy

Managing the treatment of children with epilepsy can be difficult as it requires the co-operation of the child's doctors, parents, school and carers and, of course, the child. The epilepsy specialist nurse should act as an advocate for the child, providing basic information and counselling.

Liasing with all members of the medical and nursing team, the nurse can negotiate a treatment plan that meets the needs of the child. Compliance is a major issue in treating children; the nurse specialist has a role in monitoring treatment compliance and, in consultation with the child, addressing any associated problems. Issues such as school, exams and lifestyle choices, particularly for adolescents, need to be considered when planning treatment. The nurse specialist liases with all members of the medical and nursing team, and co-ordinates all aspects of the patient's care both in hospital and at home.

One of the main roles of the epilepsy specialist nurse working with children is to provide information and education for all of the people involved in the care of the child. Information needs to be easy to understand and adapted so that children may understand it. For the child, information on safety and how to manage seizures is of particular importance.

Children with epilepsy are not ill; they have epilepsy which interrupts their daily living; the role of the health professional is to give them an optimal quality of life.

Preconception and pregnancy

The importance of preconception counselling for women with epilepsy cannot be overemphasised. The main role of the nurse is to provide information on contraception, preconception issues and seizure control and management of epilepsy during pregnancy. Preconception counselling also provides an opportunity for the epilepsy specialist nurse to review treatment and identify women who could be switched to a safer drug (for the foetus), without compromising seizure control.

In addition to providing advice and information at the preconception stage, the epilepsy specialist nurse offers information and support during pregnancy and post-partum. Liasing with midwives and obstetricians, advice is given on the management of epilepsy during labour, breastfeeding and the care of the child to minimise risk from seizures. There is evidence from the Birmingham University Seizure clinic that such a service can reduce foetal abnormalities[3] and improve the safety of the child in the puerperium[4].

Effective use of scarce resources

A debate on the effectiveness of epilepsy nursing proposed the motion that 'there is evidence to support the continued development of the epilepsy specialist nurse'. In favour of this motion, Professor George Castledine and Dr Chris Rittey, presented anecdotal evidence and case studies supporting the effectiveness of the epilepsy nurse. Against the

motion, Professor Ann Jacoby, and Dr Nicola Mills, presented evidence from controlled trials.

Professor Castledine conceded that it is difficult to provide evidence that will satisfy both health scientists and the National Institute for clinical excellence, but emphasised the importance of anecdotal and case history evidence when evaluating the role of the epilepsy nurse specialist. Epilepsy nursing in the UK is evolving slowly and, as yet, evidence-based research is limited.

From a medical perspective, Dr Rittey has found a major benefit from the education and information-gathering role of the epilepsy nurse. For example, knowing what is happening in school dramatically improves the doctor's ability to treat that patient and minimise the cognitive effect of drugs. Also, the epilepsy specialist nurse plays a particularly important role in adolescence; often such patients will not talk to doctors, but will approach a nurse. In summary, the nurse specialist eases the burden of GP's particularly those who are uneasy about dealing with epilepsy.

Against the motion, Dr Mills and Professor Jacoby presented evidence from controlled trials, which examined the impact of the epilepsy specialist nurse on a number of parameters[5–8]. Although results suggested that there was a trend toward improvement in patient knowledge, there was no effect on health status or the number of seizures reported. The results from these trials did, however, show that patients were more satisfied with their care and the number of GP consultations was reduced.

Although the audience of predominantly nurse specialists overwhelmingly voted for the motion, it was agreed that anecdotal evidence, whilst important, should be confirmed by randomised controlled trials. Only data from this type of evidence-bases research will convince National Health Trusts of the needs for the continued development of epilepsy specialists nurses. Nurses, of course, will only be convinced of the validity of such research, if it measures the outcome of what they actually do. Reduction in seizure frequency rates, although an important measure may not be the primary role of the nurse specialist and therefore an inappropriate measure of what he or she does. It may be a better measure of the efficacy of the nurse clinician in triage clinics or working in preconception clinics, or when nurses begin to prescribe.

NURSING RESEARCH IN EPILEPSY

Research proposals

A good research question or proposal is one that addresses an issue or question that affects many people, has a high impact (e.g. on cost) and is answerable within a specific time frame. Ideas can come from personal experience, the literature, or can be derived from national priorities and directives. In assessing the feasibility of a research proposal there are several factors that may need to be considered:

- Personal interest and motivation.
- Resources, such as funding, time and experience.
- Ethical approval.
- Likely co-operation of patients.

Above all, the research idea should be good science; it should be original, methodically rigorous and provide a valid answer.

The research application—ensuring success

Once an idea for a proposal has been formulated, the next challenge is to secure funding, the key to which is writing a convincing application. In ensuring the success of an application, it is helpful to be aware of the common reasons why applications fail (Table 1). For a research proposal to have the best chance of success, it must be timely, have a clear aim and demonstrate good project planning.

Table 1: Common reasons for the failure of research proposal applications.

External factors
Not within the remit of the funding body.
Not an important or high-priority topic.
Insufficient funds.
Quality of application
Methodically unclear; not good science.
Over ambitious.
Not good value for money.
Relevant discipline is not incorporated.
Researchers lack a track record in the subject area.

The study design will depend on the objectives of the study and will be quantitative (e.g. experimental), qualitative (e.g. case studies) or have a mixed method. In writing an application, it is important to specify the methods, including the sampling strategy, data collection and data analysis. Outline how the results are going to be useful, the significance and implications of the results, as well as the limitations of the study. The application should convince the funding body that the proposal is worthwhile.

As each funding body will have a specific remit, and may only sponsor certain disease types, it is important this information is known before beginning an application. Read the application guidelines carefully and note the deadlines.

Table 2: Standard section headings of research papers.

Section heading	Content
Authors	Authors—did all contribute to the work?
Introduction	Description of why the research/work was undertaken and the aims/objectives of the study.
Methods[a]	Clear description of the methods, analysis (statistics) and ethical approval.
Results	Description of the results using text, figures and tables.
Discussion	Description of the implications of the results and comparison with the results of similar studies.
Acknowledgements	Acknowledgement of those that have contributed to the study.
Conflict of interest	Indication of where sponsorship came from (e.g. pharmaceutical company).
References	Relevant references only, formatted according to the journals, instructions.

[a] Most papers fail due to the quality of the methods section.

Other things which may seem trivial but can improve the chances of success, include good presentation, spelling and adhering to the guidelines. Collaborating with experienced investigators will strengthen your application and if it is multidisciplinary, will ensure an investigator from each discipline is incorporated. Finally, always seek advice and support from colleagues and elsewhere and, most importantly, give yourself plenty of time.

Getting published

In an audit of the two hundred and four papers published in Seizure in 1999 and 2000, 17 were directly about nursing and 104 had a nursing-related content. An analysis of the authors showed that 11 of the papers had a nurse as the first or second author and 19 had a nurse as one of the other authors. Although this shows that nurses are publishing on epilepsy, there is the potential for more, especially on issues directly related to nursing.

There are publishing opportunities for nurses in primary research (e.g. clinical trials, surveys and case histories) and in secondary studies (e.g. reviews, meta-analyses and guidelines); nurses can write or contribute to papers describing the results of any of these studies.

Preparing a paper for publication will require the author to adhere to a specific layout that may be different for each journal and will be described in detail in the journal's 'instructions to authors'. In general, however, the layout is similar for all papers and follows the headings outlined in Table 2. Once a paper is submitted to a journal, it will be sent out to as many as three referees for comment. At this stage, it can be rejected, accepted or as is, more commonly the case, returned to the author with comments and suggested amendments. If the comments are addressed satisfactorily the paper should be published.

There are some common reasons for the rejection of papers:

- Study did not examine an important scientific issue.
- Study was not original.
- Small sample size.
- Flawed statistical analysis.
- Conclusions unjustified.
- Conflict of interest.
- Paper is difficult to understand.

With the increasing pressure on scientists and clinicians to publish their work and justify their position, fraud is becoming a real problem[9]. To avoid being incriminated by proxy (i.e. by being a named author on a fraudulent paper) always read a paper before putting your name to it and check the validity of the data claimed in the paper.

The next ILAE British Branch meeting in Exeter in April 2002 will host workshops for nurses on publishing papers and developing research ideas into research proposals.

CONCLUSIONS

From the debate on the effectiveness of the epilepsy specialist nurse, it is clear that a definition of 'effectiveness' (i.e. support and information vs. health status) is necessary and better tools for measuring effectiveness are required. If effectiveness is measured in terms of health status and seizure frequency, then the evidence to support the benefit of the epilepsy specialist nurse is limited. If, however, effectiveness is measured as the existence of informed and satisfied patients, who are advised on treatment choices and issues relating to their epilepsy, then there is both anecdotal and evidence-based research to support the further development of epilepsy specialist nurses.

The role of the epilepsy specialist nurse, in providing specialist information and support, is critical to the management of epilepsy and should not be underestimated. An ill-informed patient can experience drastic consequences, including failed

contraception and an increased risk of teratogenesis. It is evident from controlled trials[7,10] that the nurse specialist is effective in communicating information to the patient. Increasing the evidence-based research and the number of papers published should further strengthen the position of the epilepsy specialist nurse in his or her present role.

However there was anecdotal evidence from the meeting that the role of the specialist nurse is changing from a supportive role to a direct clinical one where different measures of effectiveness, including changes in seizure frequency, would apply. In our next conference in Exeter April 2002 (for programme see Appendix 1) we will be looking at these clinical roles in more detail, particularly nurse prescribing and nurse consultancy and posing the question how far can (or should) nurses take their clinical practice in epilepsy and if they assume full clinical responsibility, what are doctors left to do? There should be an interesting discussion!

ACKNOWLEDGEMENTS

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‘WESTWARD LOOK!’

International League Against Epilepsy, British Branch.
Annual Scientific Meeting Exeter, April 3rd–5th 2002

THURSDAY 4TH APRIL (PARALLEL SESSION)

IT’S NURSING JIM—BUT NOT AS WE KNOW IT
Chair: Mel Goodwin, Lyn Greenhill

9.30	**Nurse Prescribing—What Does It Mean for Epilepsy Nurses?** Sue Thomas
10.00	**Trust Me I’m Not a Doctor: An Epilepsy Nurse Prescribing Protocol** Lyn Greenhill, Tim Betts
10.30	**Discussion**
11.00	COFFEE
11.30	**The Nurse Consultant and the Specialist Nurse—Lessons for Epilepsy** George Castledine
12.00	**My Role As A Nurse Consultant** Jacqui Handley
12.30	**Discussion**
13.00	LUNCH
	NURSING—THE FINAL FRONTIER? Chair: Tim Betts, Lyn Greenhill
14.00	**Pushing Luck or Pushing Boundaries?** **A Discussion Session on Three Specialist Roles in Epilepsy Nursing—Triage, Preconception and Pregnancy, Vagal Nerve Stimulation** Discussants: Lyn Greenhill, Diane Splevins and Mel Goodwin
15.15	TEA
15.30	**So You Walk On Water—Now Prove It** **Making a Splash in the New NHS** Julie Ward and Mel Goodwin
16.30	**Nurses—Monstrous Regiment or the New Model Army?** **Are Physicians Left With Anything To Do?** Tim Betts, Lyn Greenhill
16.45	**Discussion**
17.00	**Close**

‘WESTWARD LOOK!’

FRIDAY 5TH APRIL (AFTERNOON))

WORKSHOPS FOR NURSES

14.00 **WORKSHOPS** (delegates may choose 2 out of the 6)

(A) **Epilepsy Nurse Prescribing—Practical Aspects**
Lyn Greenhill

(B) **Nursing Research In Epilepsy**
Judith Lanfear and Mel Goodwin

(C) **Publishing/Presenting Your Research**
Nicola Pickard

(D) **A Primary Care Epilepsy Service**
Jon Sutcliffe and Andy Hansen

(E) **Getting the Best Out of NHS Management**
Julie Ward

(F) **Complementary Therapies in Epilepsy**
Tim Betts and Rebecca Cooke

15.15 TEA

15.45 **WORKSHOPS CONTINUE**

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Self-assessment questions

Which of the following statements are true?

Question 1. Counselling issues identified in several studies as important for people with epilepsy include:

(a) depression
(b) sexual health
(c) emotional support
(d) information
(e) anxiety

Question 2. People with epilepsy in several studies were found to lack knowledge in these areas:

(a) new medication
(b) nursing care
(c) photosensitivity
(d) driving regulations
(e) type of epilepsy

Question 3. Of the following options which have been found to be essential to satisfy patients educational needs in various studies?

(a) leaflets
(b) specialist epilepsy nurse
(c) group discussion
(d) information tailored to the patient
(e) video material

Question 4. The first epilepsy specialist nurse was appointed in:

(a) Manchester
(b) Birmingham
(c) Royal Marsden Hospital
(d) Darlington
(e) Doncaster

Question 5. In controlled trials epilepsy specialist nurses have been shewn to:

(a) reduce seizure frequency
(b) improve patient knowledge
(c) reduce number of GP consultations
(d) introduce new medication
(e) increase patient satisfaction

Answers

Which of the following statements are true?

Question 1. Counselling issues identified in several studies as important for people with epilepsy include:

(a) is true.
(b) is false.
(c) is ture.
(d) is true.
(e) is true.

Question 2. People with epilepsy in several studies were found to lack knowledge in these areas:

(a) is true.
(b) is false.
(c) is true.
(d) is true.
(e) is true.

Question 3. Of the following options which have been found to be essential to satisfy patients educational needs in various studies?

(a) is false.
(b) is false.
(c) is false.
(d) is true.
(e) is false.

Question 4. The first epilepsy specialist nurse was appointed in:

(a) is false.
(b) is false.
(c) is false.
(d) is false.
(e) is true.

Question 5. In controlled trials epilepsy specialist nurses have been shewn to:

(a) is false.
(b) is true.
(c) is true.
(d) is false.
(e) is true.